

New service for cancer patients with learning disabilities

In 2000, BILD highlighted the lack of information for people with learning disabilities about cancer. It is pleasing to see this being addressed by the launch of a new cancer information service.

See [BILD cancer project](#)

Macmillan Cancer Relief has funded the first information service of its kind to meet the needs of cancer patients with learning disabilities. The project has been developed following recent studies which show this group of patients miss out on vital information and support because they have additional needs to those of the general public.

Around 1.2 million people in UK have learning disabilities - approximately 25 per 1000 people. Figures show cancer incidence in people with learning disabilities is increasing and indicate that around one in ten will die of cancer.

The most striking difference between people with learning disabilities and the rest of the population is the high incidence of gastro-intestinal cancers. People with Down's Syndrome are also at risk of cancer - there is a 20/30 fold increased risk of childhood leukaemia and an increased risk of testicular cancer in men, but perhaps a lower risk of breast cancer in women.

The Macmillan Network Information and Support Service for the Learning Disability Community has been developed as a joint venture between Macmillan and The National Network for Palliative Care of People with Learning Disabilities (NNPCPLD). The much-needed service offers telephone and email support, guidance and information on caring for people with learning disabilities who have cancer to healthcare professionals, learning disability staff or carers of cancer patients. Opening hours of helpline - Monday, Wednesday and Friday 9 - 6pm. The telephone number is 01223 460 473 or email info@natnetpald.org.uk

Information on cancer is essential for patients with learning disabilities who have palliative care needs and could even help to save lives. Some studies have found that a high number of cancer deaths among people with learning disabilities were probably preventable. There are several reasons why people with learning disabilities are vulnerable including; difficulty in accessing screening programmes, difficulty in making healthy lifestyle choices e.g. smoking or diet which can lead to cancer or problems in communicating signs or symptoms, such as fatigue or pain which may indicate cancer.

Linda McEnhill, Macmillan Information and Support Service Manager, says, 'There are so many issues to consider. It's important to be able to break the news of cancer to patients in a way they can understand or to be able describe how treatment works to people with learning disabilities. We are pleased to have this much needed service up and running for this hard to reach audience. There is a growing demand for this type of information that needs to be met.'

Richard West is deaf and has learning disabilities - his father died of cancer. He says, 'I used to visit my father in hospital, no-one told me what was going to happen to him. I didn't know he was going to die. If someone had talked to me, it would have been easier to find out what was going on. When he died the nurse didn't tell me I could see his body. It would have been better if she had written

everything down so I could have looked at it later. People with learning disabilities should be given the same information as anyone else, with pictures or photographs so it is easier to understand.'

The Macmillan Information and Support Service is the lead in its field and will provide information and support on caring for people with learning disabilities who have cancer or palliative care needs - details of local organisations, a range of literature and resources, training prospects, and signposting to other sources of support are all offered.

People with learning disabilities who have a friend or relative with cancer also have different information needs that need addressing and Macmillan's Information and Support Service offers advice and support on these specific information needs also.

For more information, please email: info@natnetpald.org.uk